

End of life decision planning in the perioperative setting: the elephant in the room?

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What previous generations called ‘the art of dying’ is undergoing a renaissance as an important aspect of healthcare delivery. In his recently published book, ‘Being Mortal’,¹ and accompanying Reith lectures, surgeon and author Atul Gawande has turned a spotlight on the increasing medicalization of death. In 2003 national figures in England and Wales showed that 81.9% of those who died did so in some form of medical institution.² This medicalization of death may have led to a disconnect between the reality of ever-escalating medical care in a hospital environment and the desires of the patient. In an attempt to avoid paternalistic behaviours and embrace the ideals of autonomy and patient centred care, physicians should aim to provide fully informed consent that respects the values and beliefs of the individual.³ Robust informed consent has been synonymous with surgical procedures for decades, however only recently has the idea of shared decision-making in end of life care gained momentum. Historically these discussions take place after the patient has failed to make a good recovery or has deteriorated rapidly. At this point he/she often lacks capacity to engage in meaningful end of life decision-making. All too often the clinician and patient’s family must gather information by proxy with little direct insight into the patient’s actual wishes. An advance discussion with patients and documentation of their views and wishes can be invaluable at such difficult times. The Mental Capacity Act⁴ codified existing law and provided a variety of ways that patient’s can make advance decisions about their healthcare. Uptake remains low however, with only 8% of the general public in the UK having an advance care plan.⁵ The question has now become how do we encourage more people to engage in these conversations and start to express their wishes for their own end of life care.

More surgery; more risk

In the UK there were 10.5 million completed procedures and interventions in 2012–13.⁶ Although less than 1% of patients undergoing surgery die during that hospital admission, there are still 20 000–25 000 deaths in the perioperative period each year.⁷

This becomes particularly important within the context of an ever-ageing population. In 2010 the population of England aged more than 65 was 16% and this is projected to increase to 23% by 2035. Additionally the fastest population growth is observed in the oldest age group; between 1985 and 2010 the population of over 85’s doubled from around 0.7–1.4 million and is expected to reach 3.5 million by 2035.⁸ There is a wealth of data showing

that the increasing age of a patient is associated with increasing morbidity and mortality after surgery. Examining the older surgical population the REASON trial highlighted an increased mortality as patients get older. 30-day mortality for all types of surgery increased from 4% for patients in their 70’s to 12% in the 90+ age group.⁹ In the US it has been demonstrated that of those more than the age of 65 years who die, nearly a third will have undergone an inpatient surgical procedure in the previous year.¹⁰

Future projections are of an increasing number of surgeries being performed in an ever-growing high-risk group of patients. It is important to recognize that of those patients admitted to hospital 29% of them will die within the year, including 17% of ‘surgical’ patients.¹¹ Whilst for the vast majority, surgery proceeds without any complication, there is a significant, and growing, subset for whom this is not the case. It would seem prudent that perioperative encounters are seen as opportunities to begin the process of a constructive and documented discussion of end of life wishes.

The care we want

In 2013 the Liverpool Care Pathway was withdrawn from use in the NHS, due in part to concerns that it had become a generic ‘tick box exercise’ and did not provide the personalized care patient’s at the end of life require.¹² The National Care of the Dying Audit in England found that only 46% of patients thought capable of participating in discussions about their end of life care had them documented and 24% of relatives did not feel they were involved in decisions at all.¹³ Since then the Leadership Alliance for the Care of Dying People¹⁴ have published five ‘priorities of care’ (Table 1) for those who are considered at risk of dying within the next few hours or days. It is hoped that these principles will provide a framework for local organizations to produce systems that deliver the quality of care that people expect for their dying relatives and loved ones. Its remit and focus is primarily on the care a person receives in the hours and days before they die. It reiterated the responsibilities of healthcare professionals regarding treatment refusal, however it does not focus on ways we can ensure healthcare professionals understand more about a patient’s wishes, particularly in those who lack capacity.

Advance Care Planning is a structured discussion between a patient and his/her care providers and family to make clear a person’s wishes and expectations. It includes a person’s concerns, personal values and goals and particular preferences for types of care and treatments.¹⁵ At present there appears to be a

Table 1 Priorities of care for the dying person¹⁴

The possibility (that a person may die within the next few hours or days) is recognized and communicated clearly, decisions made and actions taken in accordance with the patient's needs and wishes, these are regularly reviewed and decisions revised accordingly.
Sensitive communication takes place between staff and the dying person, and those identified as important to them.
The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
The needs of the family , and others identified as important to the dying person are actively explored, respected and met as far as impossible.
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

separation between peoples stated desires towards the end of life and the reality of the care they receive. When asked the **location** in which they would prefer to **die** 67% of people say that they would **prefer** to be at **home**.¹⁶ No other location is preferred by more than 1 in 20 people, yet currently **only 18%** of people are able to go **home** to **die**.² There is also evidence that with use of advance care planning, there is a decrease in the use of life-sustaining treatment and hospitalization and an increase in the use of hospice and palliative care,¹⁷ suggesting that when patients are actively involved in decision-making, they may opt against ever escalating medical care. It is interesting that a recent **survey looking at doctors** in the **US** has shown that when terminally ill, **88.4%** of respondents would **choose not** to receive **CPR**.¹⁸ We are currently running a survey looking at medical professionals own desires for end of life care and it will be interesting to see whether doctors are now prescribing treatments for patients that they would choose to forego themselves.

The elephant in the room

An ICM survey of the UK population in 2006 found that only 34% have talked about their end of life wishes, despite 80% thinking that it is important to do so.¹⁹ Perhaps the reasons for not discussing death is that it is seen as unpleasant, discomfoting and even macabre. The truth however may not be so clear-cut and even contrary to this perception. For the first time, in 2013 the British Social Attitudes Survey,¹⁶ a national wide-ranging survey with over 3000 participants, enquired about people's feelings regarding death and their planning for end of life. 70% of respondents said that they would feel comfortable discussing death and only 13% said that it would make them feel uncomfortable. It concurred with the 2006 ICM survey¹⁹ in that **less than half (45%) have had discussions regarding their wishes in relation to any aspect of their end of life plan**. Whilst there are a group of people who wish to avoid these conversations because they said that it would make them uncomfortable, even at its highest in the >75's age category, it only accounts for 18% of respondents. The remaining 80% can broadly be divided into two categories; younger people tend to avoid these discussions as death simply seems a long way off, and an older population who have a growing concern that such discussions would make other people feel uncomfortable.

If the public really is as open to these sorts of conversations as the data suggests then the time for having such discussions should be as soon as possible. The time to think about this is not when unwell, when patients may be excluded from such decisions because of a lack of capacity, but rather early ahead of cognitive decline. The use of a validated questionnaire or document handed to patients at a routine doctor's appointment may well provide a reason either to think about something that they

have not previously considered or a route to open up a conversation with family or friends. Such information, though not considered binding, might then be used at a later date as a discussion aid between patients and doctors and doctors and relatives.

Is preoperative assessment the right place to start a discussion?

With around **80%** of those **undergoing elective** operations being **seen** at a **preoperative assessment** clinic,⁷ introducing conversations regarding end of life wishes for those attending would certainly bring it to the attention of a large number of people pre-emptively. In particular it would **capture** those who should be considered **high risk**, but there may also be a role for highlighting these issues to as large a number of people as possible.

There would undoubtedly be a concern that opening up such a conversation with a patient before having an operation would create a heightened level of anxiety. It cannot be denied that this is a potential problem, however the combination of an appropriate explanation that this is routine, and the fact that most pre-assessment clinics run weeks in advance of planned surgery, should provide patients and professionals reassurance. The process of surgical consent most often proceeds with rational discussion even when patients are presented with information that might be considered upsetting. A US study looking at introducing advance care planning before patient's undergoing cardiac surgery, found no difference in anxiety levels between those having such discussions and those not.²⁰ There may however be a question of whether healthcare professionals are currently sufficiently trained to lead such consultations. It was noted in the review of the LCP¹² that whilst many of the competencies required may be generic, such as the ability to empathize and communicate effectively, there remains a need for better training in regard to the specifics of end of life discussions.

Interestingly the main opposition towards introducing such an idea may come from healthcare professionals as opposed to patients. A **survey of US surgeons found that 54% would refuse to operate on a patient who had an advance directive that would limit postoperative life supporting therapy**.²¹ This raises an important debate in regards to the recent move in the UK to **publish surgeons' performance data**. Do these figures **incorporate** the important **nuances of patient centred care**, or will it result in a push to either **avoid intervention** altogether, or **force** patients to have the **maximal available** medical **treatment** even if it is not what they would want? If a patient was to undergo a high quality consent process with appropriate advance care planning and chose to limit interventions at a certain point, would this not be a good example of the patient centred care?

In conclusion, it seems clear that the next decade will bring a markedly aging population and the complexity of end of life care

planning will increase. At the heart of providing the care that people want when they die is in understanding the individual values, beliefs and concerns for each person. The nature of critical illness may prevent direct and effective discussions with individual patients. To ensure people receive the care they deserve and the outcome they desire, we are going to have to begin that conversation early, when capacity is intact. With an increasing number of people passing through preoperative assessment clinics each year, whom appear to be open to discussing end of life care, there is an opportunity to engage in a constructive dialogue which seeks to empower patients, reduce harm and suffering and support family members.

Declaration of interest

Professor Mythen is a BJA Editorial Board member. No other interests have been declared.

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Quality care in anaesthesia: roles of regulation and accreditation

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Delivering best patient outcomes and satisfaction within a culture of optimal safety is the ultimate goal of everyone who commits their working life to the UK National Health Service (NHS).

Nevertheless, history tells us that, despite these laudable intentions, 'quality care' has not always been delivered to patients by the NHS. The 'Bristol heart scandal' shocked the world. The